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ABSTRACT

Federal legislation mandates that states participating in early intervention provide services to children with disabilities from birth to their third birthday. The early intervention population is a diverse group, with African Americans comprising the second largest group served. African Americans may have differences in child rearing practices that could affect the way services should be delivered to these families. Urban and rural caregivers of young children with disabilities may also need different service delivery. Differences based on geographic location, such as availability of resources, access to resources, and familial contact, may impact how services should be delivered. A study compared the self-perceived needs and sources of supports of rural and urban African American and White caregivers of young children with disabilities. Participants were primary female caregivers of young children with special needs currently enrolled in Idaho's early intervention program (over 87 percent of the early intervention population). Results indicated that African American and White caregivers differed significantly on the overall need they reported. Urban and rural caregivers did not differ significantly on overall level of need. African American and White caregivers did not differ significantly on the overall level of support they reported, but urban and rural caregivers did differ significantly on overall level of support. Implications for practice are discussed. (TD)

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ED 476 205

A Comparative Study of the Needs and Sources of Support of African American and White urban and rural Caregivers of Young children with Special Needs

Research, Legal, Philosophical, and Clinical Background

Early Intervention (EI) for Young Children

Federal legislation mandates that states that participate in Early Intervention (IDEA, 1997) provide services to children from birth to the third birthday, who have a diagnosed disability, including developmental delay. This assures services to the very youngest children with disabilities. The premise of this legislation is that early intervention for young children with disabilities will enhance their development and maximize their potential.

Cultural Diversity in EI

If grouped by ethnic/racial background, the children and families who are served in this state's early intervention program, are as follows: 52.9% White (Non-Hispanic), 34% Black (Non-Hispanic), 7.4% Hispanic, 3.9% Multiracial/Other, 1.7% Asian/Pacific Islander, and .1% American Indian/Alaska Native (BCW RBB Data, 2001); these proportions mirror the national percentages. These percentages demonstrate that the EI population is a diverse group. It has been documented that service delivery has not always taken into account this fact (Sontag & Schacht, 1993), and has been patterned after a mold that does not recognize this diversity. African Americans comprise the second largest group that is being served in the program, yet they are infrequently queried nor are their needs and priorities specifically addressed in delivery of services.

Limited Research With Participants Who Are From Diverse Backgrounds

Research in the past has involved children and families that are mainly middle class and White (Palmer, Borthwick-Duffy, & Widaman, 1998; Turnbull & Ruef, 1997; Bailey, Blasco, & Simeonsson, 1992a). This is only representative of one of the many groups that are served in EI. There is increasing recognition that results may or may not be generalizable to the other groups. More recent research has begun to document that these other groups may have issues, points of views, or backgrounds that must be taken into account in order to provide adequate and appropriate services.

Suspected Areas of Difference

The question of whether or not there is a need for a different type of service delivery for African Americans needs to be investigated. At this point, it is suspected, but not necessarily documented, that there is need for a different type of service delivery. Needs may or may not be different enough to warrant a tailored type of service delivery. It is suspected that there is a need for a different type of service delivery because there is a difference in the proportions of AAs who utilize school-aged special education services and who utilize Part C services (US Department of Education, 2000; Patton, 1998). There appears to be underutilization of the early intervention system by [minorities] (Arcia, Keyes, Gallagher, & Herrick, 1992). African Americans may have differences in child rearing practices, they may have differences based on their social status in society, or they may have differences based on being involuntary immigrants (versus voluntary immigrants); these potential differences may affect the

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way services should be delivered for these families as well as the families' views about service delivery and/or EI in general. Service delivery should be based on the specific needs of the individuals who are being served.

Another area of suspected need for different type of service delivery for urban and rural caregivers of young children with disabilities. Differences bought on by the geographic location of the families, such as, availability of resources, access to resources, and familial contact, may impact how services should be delivered for these families.

Research Literature

Literature that is relevant to this proposed study lies in the areas of family centered care, the diversity that is represented by these families, the needs and sources of support for these families, and how these needs and supports are mediated by the background and geographic location from which these families come.

Family Centered Care

One of the cornerstones of the field of Early Intervention is that of family-centered practice (Mahoney & Bella, 1998; Bailey, Buysse, Edmondson, & Smith, 1991; Dunst, Johanson, & Trivette, 1991). The term family centered care represents a set of beliefs, attitudes, and principles that guide the delivery of services to young children with special needs and their families (Bruder, 2001, 2000). Since originally mandated in 1986 (PL. 99-457, Part H [now Part C]), family centered care has evolved from an idea into a practice (Turnbull & Turnbull, 2001; Beckman, Newcomb, Frank, Brown, Stepanek, & Barnwell, 1996; Pearl, 1993). In this practice, and as it is written in the law, family centered practice views the family's needs and beliefs as equally important as those of others on the early intervention team. There is also the belief that the family's priorities should be the guiding force in service delivery (Turnbull & Turnbull, 2001; Bruder, 2000). Since Inglesias and Quinn (1997) remind us that culture is a universal context and that all children and families, staff, and organizations bring values and beliefs to early intervention situations, culture cannot be left out of this practice of family centered care. Sometimes interventionists are looking to the broader goal, while families are looking at the "little things" (Beckman, et al., 1996). Adherence to a policy of family centered care can become problematic when families are from different backgrounds than the people who are providing the services.

Diversity

Even when diversity is recognized, it is difficult to effectively include the voices of families who are from diverse backgrounds into service delivery (Harry, Kalyanpur, & Day, 1999; Kalyanpur & Harry, 1999; Harry, 1997; Sontag & Schacht, 1993; Harry, 1992a, 1992b). There is an increasing need for research that seeks to address family centered practice within the context of families from diverse backgrounds (Reyes-Bianes, Correa, & Bailey, 1999; Chen, Brekken, & Chan, 1997; Hanline & Daley, 1992). There is also a need for research that addresses the needs of families from specific cultural backgrounds (Reyes-Bianes, et al., 1999; Harry, 1997; Chang & Pulida, 1994; Polk, 1994). There is a need for research that includes families who are from diverse backgrounds because the number of persons who are from diverse backgrounds has increased steadily over the last twenty years (United States Bureau of Census, 2002). Nearly 30% of the population of the Unites States is of non-European ancestry; compared to just 12% in 1970, this represents a significant increase (Lynch & Hanson, 1998). This change in the diversity in the general population creates a domino effect on early intervention systems.

The change in the diversity in the general population has not systematically been replicated in the early intervention system's population. There has been some change, but not at the same rate as the general population (Hains, Lynch, & Winton, 2000). Increased diversity in the general population has created a mismatch between service providers and the families who are enrolled in early intervention systems. Providers are still predominantly White and female, while the population they serve is becoming increasingly diverse (Hains, et al., 2000; Winzer & Mazurek, 1998; Lynch & Hanson, 1993). Within the diversity that these families represent are a large number of young children with disabilities and their families who are African-American. In Georgia, 34 % of the children and families who are being served in the early intervention program are of African American descent. These children are the second (to White) largest group of children receiving Part C services (BCW RBB Data, 2001).

Due to the dichotomy of service providers from one background and children and families they serve from another, researchers have called for increased sensitivity on the part of service providers to the culture(s) of the

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families they serve (Park & Turnbull, 2001; Tabors, 1998; Harry, 1997; Dennis & Giangreco, 1996; Barrera, 1993; Harry, 1992b; Hanson, Lynch, & Wayman, 1990). There has also been research documenting success in the designing and implementation of programs that have a strong focus on servicing the needs of young children who are from diverse backgrounds and their families (Washington, 1996; Gonzalez-Mena, 1992; Bruder, Anderson, Schutz, & Caldera, 1991).

Family diversity

One definition of "family" is a group of people, related by blood or circumstance, which rely upon one another for security, sustenance, support, socialization and stimulation (Chynoweth & Dyer, 1991). This definition of family allows us to include individuals who are not related by blood, but by circumstance. Such circumstances include, but are not limited to, children and families who identify themselves as foster families, grandparents who are raising their grandchildren, and a myriad of situations that involve young children being reared by persons other than their biological parents. The term "caregiver" encompasses the various possibilities of how individuals identify themselves as a family. The federal definition of "parent" includes natural/adoptive, guardian, or person acting in place of parent, assigned surrogate, and foster parents (IDEA, 1997). This definition too, recognizes a myriad of family formats. Our society's educational and social systems must recognize that there are differences that must be addressed when dealing with families, specifically families who are from culturally or linguistically diverse backgrounds (Lynch & Hanson, 1998; Harry 1992a; Anderson & Goldberg, 1991; Anderson & Fenichel, 1989). This is especially true for systems that propose to be family centered, such as, the early intervention system.

Needs and Sources of Support

In Early Intervention, families are enrolled in the program for a short time (maximum three years); therefore, it is imperative to plan ahead from the beginning. Being able to identify a family's needs immediately allows planning for the provision of the resources or supports that are necessary to fulfill these needs (Turnbull & Turnbull, 2001). Since needs are fulfilled utilizing supports within a family's community, it is important to ascertain directly from the appropriate person(s) what their needs and sources of support involve. This allows service providers to enable and empower families (Dunst, Trivette, & Deal, 1988). As sources of support may be cultural, economic, social, or spiritual (Bradley, 1992), early intervention needs to recognize that these types of support may already exist in communities. Persons who are from the same cultural, economic, social, and spiritual backgrounds might have created systems that work for them and are currently being used. It is imperative that early intervention programs find out what these systems are from the persons who use them. Systematic attempts must be made to unveil this information. The families themselves should be the ones to provide this information.

This information will then be provided from the families' unique perspectives, which includes, but is not limited to, cultural identity, recent and past experiences, or the location in which the families live. Location is important because it often drives the person's perspective. The perspective of someone who lives in a rural environment (locations with fewer than 2500 residents) is very different from that of a person who lives in an urban environment (more densely settled areas) (Economic Research Service, 2002). Though the majority of the U.S. population resides in rural environments (United States Bureau of Census, 2002), the issues surrounding those that reside in urban environments are often so great that they warrant equal attention.

Need and Support Mediated by Geographic Location

One of the challenges that face early intervention in states, such as the one in this study, is the ability to serve families who reside in both urban and rural environments while still being able to meet the unique needs of each. Turnbull and Turnbull (2001) and Kozol (1995) tell us that rural and urban factors significantly affect the way services are delivered to children and families. Researchers have documented significant differences in the need for tailored service delivery models for both rural (Fenichel, 2000; Butera, 1998; Watson & Bennett, 1993) and

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urban populations (Unger, Jones, Park, & Tressell, 2001; Baxter & Kahn, 1999; Fantuzzo, Stoltzfus, Lutz, Hamlet, Balraj, & Turner, 1999; Kuchler-O'Shea, Kritikos, & Kahn, 1999; Boone & Coulter, 1995). Taking into account the views of caregivers who are White and who are African American (the two largest groups who are being served in the early intervention program) and who reside in urban and rural locations enabled the researcher to ascertain a more comprehensive picture of the needs and sources of support for caregivers of young children with disabilities.

The purpose of this study was to compare the self-perceived needs and sources of supports of African-American (AA) and White caregivers of young children with disabilities. By determining and comparing their needs and supports, EI can be more responsive to these needs, and perhaps broaden the network of support that is available for these families. The field of early intervention can use information gained from such research to possibly identify more supports or alternative supports and to respond to the unique demands of children and families who are from culturally diverse backgrounds. Family centered care, being one of the hallmarks of the field of early intervention, can be strengthened by gaining information that can be used to modify and enhance appropriate family-centered and culturally sensitive EI practices (Turnbull & Turnbull, 2001; Bruder, 2000).

Theoretical Foundation

The theoretical foundation within which this proposed study is grounded it that of family systems theory (Turnbull & Turnbull, 2001; Bronfenbrenner, 1986; Bronfenbrenner, 1979). Family systems theory is grounded within the greater general systems theory, which states that all living systems are composed of interdependent parts. What affects one part is likely to affect other parts (Beckman, et al., 1994; Von Bertalanffy, 1968). Family systems theory applies general systems theory to the living unit of the family, with an emphasis on interactions and relationships. It is also closely tied to the work of Urie Bronfenbrenner. Early intervention as a whole recognizes that the family, including families of young children with disabilities, is a living entity that is made up of interdependent parts (Turnbull & Turnbull, 2001; Unger, et al., 2001; LeLaurin, 1992; Dunst, Trivette, Hamby, & Pollock, 1990; Bailey & Simeonsson, 1988; Fewell & Vadasy, 1986). If one or more of these relevant parts is not functioning as intended, the other parts are subsequently affected. (Turnbull & Turnbull, 2001; Boss, Doherty, LaRossa, Schumm, & Steinmetz, 1993; Thomas, 1992; Becvar & Becvar, 1982).

Variables and Instrumentation

Hypotheses and Research Questions

The hypotheses utilized in this study were nondirectional alternative hypotheses (independent variables: AA, White, Urban, Rural, *will differ* on dependent variables: Needs and Support). The independent variables of ethnic/racial background were defined by US census definitions for African American and White. The independent variables for geographic location also utilized the census definition for urban. Due to ambiguity of definitions for rural, Goreham (1997), was instrumental in clarifying the definition for rural. The dependent variables were defined and characterized by the Family Needs Scale (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1987) and the Family Support Scale (Dunst, Jenkins, & Trivette, 1986).

Six overall questions/10 permutations:

- Do caregivers differ by race/ethnicity (AA, White)?
  - On family needs?
  - On family sources of support?
- Do caregivers differ by location (urban, rural)?
  - On family needs?
  - On family sources of support?
- Does the interaction race/ethnicity and location have an effect?
  - On family needs?
  - On family sources of support?

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Participants/Setting/Implementation

Participants were mothers (or primary female caregivers) of young children with special needs. The families were currently enrolled in the state's EI program. They were either African American or White (total over 87% of the EI population) and the resided in urban and rural portions of the state. They were recruited through the EI program service coordinators

Data were collected at the participants' place of choosing, typically their homes. Some data were collected at local health district office and other mutually agreed locations. Upon meeting, the researcher administered the data collection instruments, by reading all instruments aloud (for consistency and issues of literacy). Upon completion, the incentive for participation ($10 cash) was given.

Data Analyses and Results

Analysis of Variance (ANOVAs) statistical procedures were done to determine if the differences reported by the families on the overall (averages of composite scores) levels of need and overall levels of support were significant. MANOVA procedures were done to determine if the families reported statistically significant differences on subscales (averages of subscale scores) of need and subscales of support. All analyses addresses ethnic/racial and geographic location differences.

Family Needs

The general results of the ANOVA analysis for family needs are as follows: The relationship between race/ethnicity and the composite of need was significant. African American and White caregivers differed significantly on the overall need they reported. Urban and rural caregivers did not differ significantly on their overall level of need reported. The interaction of race and location as it affects need was not significant.

The MANOVA that examined relationship between race, location, and the four subscales of family need yielded the following results: African Americans and Whites differed significantly on all the subscales of family needs; there was no significant difference between the urban and rural respondents on any subscale of family need; there was a significant interaction effect of race and location as it affected the personal and family growth subscale of family needs. The four estimated marginal means for all groups (AAU, AAR, WU, and WR) on personal and family growth interaction were compared. The difference between WR and AAR was not significant; however, the difference between the means for AAU and WU caregivers was significantly different. Furthermore, while AAU and WU caregivers had distinctly different means from each other, both means were significantly different from those of the and WR and AAR caregivers, with AAU caregivers expressing the highest mean for need.

Family Sources of Support

The general results of the ANOVA analysis for family sources of support are as follows: The relationship between race/ethnicity and the composite of support was not significantly different. African American and White caregivers did not differ significantly on the overall level of support they reported. Urban and rural caregivers, though, did differ significantly on their overall level of support reported. The interaction of race and location as it affects overall support was not significant.

The MANOVA that examined relationship between race, location, and the subscales of family support yielded the following results: African Americans and Whites did not differ significantly on any of the subscales of family sources of support reported; there was a significant difference between the urban and rural respondents on two subscales of family support (formal/informal kinship and social/organizational support). For the interaction effect of race and location as it affected the subscales of family support, one subscale was found to be significant, that is, spouse/partner support. Actual group means are listed in Tables 14 and 15. The four estimated marginal means for all groups (AAU, AAR, WU, and WR) were compared. The difference between the means for WU and AAU caregivers was not significant; however, the difference between the means for AAR and WR caregivers was significantly different. Furthermore, while AAR and WR caregivers had distinctly different means from each other,

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both means were significantly different from those of AAU and WU caregivers. Caregivers who were WR expressed the highest means for support.

Limitations

Limitations of this study include the representativeness of the sample, the generalizability of data based on racial/ethnic comparisons, and limitations of the instrumentation.

Representativeness of the Sample

The representativeness of the sample may be limited because participation was voluntary and the caregivers were approached and asked if they were willing to participate. Refusal to participate was not recorded; therefore, it is not known how many families (that were approached) refused to participate, and consequently, their reason(s) are not known. Because the relationship between need and support and willingness to participate is not known, it could be concluded that those who chose to participate were just as likely to be needy/not needy or supported/not supported as those who chose not to participate.

Generalizability of Data Based on Racial/Ethnic Comparisons

"Ethnic/racial background" and "culture" are used synonymously in some sources of the literature to designate that a group of people have shared values, beliefs, and ways of being. This premise is predicated on the fact that if people share a common experience, background and way of being, then conclusions can be drawn and generalizations can be made about them (Hanson & Lynch, 1992; Hanson, et al., 1990). If conclusions are drawn they must be tested, repeatedly, before generalizations are made. This research is one such attempt to test these conclusions and to query the persons for whom conclusions are being drawn. Other researchers (Chen & McCollum, 2001; Garcia, Perez, & Ortiz, 2000) are doing similar work; however utilization of participants who are African American is not as common. In order to draw conclusions about groups of people, it is beneficial to query those people directly, which is what this research has done.

Though systems are urged to acknowledge that diversity exists across groups, there are within group differences that must not be overlooked. It should never be assumed that because families are from a certain background, that their beliefs are similar. Lynch and Hanson (1998) speak of a "continuum of cultural identification." They caution the reader that "[a]ssumptions about an individual's behavior based on a cultural label or stereotype may result in inaccurate, inappropriate, or harmful generalizations" (Lynch & Hanson, 1998). The 'individualized" in the IFSP is a reminder that services are to be tailored to the specific family's needs and priorities for their child. Persons from some groups may or may not express similar needs and priorities. It is important to find out what those needs and priorities are. Caution however must still be exercised to avoid over generalizing based on what is reported by groups of these caregivers (Laosa, 1991). Instead, systems should build on patterns or themes that emerge from the responses to tailor service delivery.

Limitations of the Instrumentation

Issues regarding limitation of the instrumentation used in this study are relevant for both the Family Needs and the Family Support Scale. Both instruments are on a five point Likert scale. They offer a "Not Applicable" or "Not Available" choice respectively. On the Family Needs Scale, "Not Applicable" could be interpreted as "this item really does not apply to me and my family" or it could be interpreted as, "since we have the resources to address this, it really is not an issue I cannot deal with."

The subscales for family need and the subscales for family sources of support were moderately to highly correlated. Though it would be preferred that these correlations show that the subscales are independent constructs, it is acceptable that they are not, as the purpose of looking at the subscales in addition to the overall need and overall support, was to determine specific types of needs and support.

Implications/Summary

The findings from this research may have implications regarding family centered practice, culturally appropriate and general service delivery, and public awareness. In order to maintain the mandate of the law, which

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ensures family centered practices in early intervention, programs could use these results to shape policies regarding families who are African American and families who are White. Truly family-centered service delivery is service that takes into account the families' culture and how that relates to their needs and supports.

Urban and rural caregivers reported different levels and types of supports. Public awareness activities and service delivery should reflect the needs of both urban and rural caregivers, especially in regards to family supports.

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